Notes from DDA Listening Session #3: Columbia, Maryland

October 27, 2014

Self Advocate Session

This session was one of a series in each of the four regions of the State. There were separate listening sessions for self-advocates, families and providers in each region. Across all of the meetings, a number of themes emerged. These included the following:

- A desire for more frequent and understandable communication with DDA (both in writing and in person)
- A need for improved Resource Coordination (emphasizing the skills and activities that are important to the individuals and families served)
- A concern that the system lacks trust at all levels, and a strong desire to build partnerships (between the state and self-advocates, families, advocates and providers)
- A need for improved consistency and staff capacity at DDA

The feedback at each of these sessions was thoughtful and impassioned, shining a light on the need to work together to improve the system for individuals and families.

In each session, the facilitators asked the following questions:

What things are going well?

What are challenges/barriers and/or things you would like to change?

If changes are made to the system, what are things that should be kept?

The notes below reflect the feedback from the session participants. In some sessions, the comments mainly reflect areas where improvements are needed.

| Areas for Improvement: | | | | |
|------------------------|---|--|--|--|
| | One individual in attendance attends the UMBC program and Arc Howard during school breaks. She is doing an internship right now and hopes to get a paid job and to live in her own house. She is learning things that will help her achieve her goals. She would like to continue receiving the supports. | | | |
| | There was an interest in getting clarification on the role of Resource Coordinators. | | | |
| | One individual expressed concern about health care and how to get more money. She is on medication and is being told that there isn't enough money. | | | |

| Areas for Improvement: | | | |
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| Aleas for improvement. | | | |
| | In addition, she needs more support at home but right now she can only get support until 6pm. She needs it later. | | |
| | There was great concern about others who do not get any support. | | |
| | Transportation is very expensive and getting more expensive every year. There is uncertainty where all of the money going. | | |
| | Staff (especially in new directions) should be able to receive health benefits. | | |
| | There is a recommendation that DDA consider providing for retirement for direct support staff. Community staff should receive comparable benefits s institutional staff. | | |
| | One young man stated that he wanted to live on his hown but did not know that was an option. He wanted t go from agency to New Directions. The provider told him they could provide what he wants and needs so he went with an agency. He has not received services in two years Family has tried to get help from many organizations and government. No satisfaction to this point. Thinking about new directions again. He is very frustrated and resource coordination has not been helping or listening to what he wants. | | |
| | A woman who works in Annapolis Junction noted that there needs to be more funding from DDA. She needs a roommate. | | |
| | One individual expressed worry about her workshop closing down. But she said she does not like it because she is bored and the noise level is getting worse. She is getting a new house and a new roommate. | | |
| | There was a strong recommendation that DDA and RC hire more people with disabilities. Everyone in the room agreed with this recommendation. This would help make sure that the systems understood the challenges better. | | |
| | One woman was on the waiting list to live on her own. She really wishes that services are available. | | |
| | There was great concern about the 82 hour cap. Concerned that this puts people in jeopardy of not getting the supports they need and perhaps being institutionalized. DDA has been holding very strictly to this rule recently. This has come up in multiple meetings. | | |
| | There was also strong concern about what happens when people go into the hospital. DDA will not pay for the supports but people need things over and above what the | | |

| Areas for Improvement: | | |
|------------------------|--|--|
| | hospital will do, and it is important to have support while there. | |

Notes:

General discussion and/or information not included in specific comments:

This self-advocate meeting had the best attendance of any across the state. There was great discussion regarding the need for greater support and services, and important points about making sure staff receive pay and benefits so that they will stay.